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ABSTRACT

This handbook provides information on autism to enable Colorado parents and educators to recognize early symptoms in young children and to provide for early intervention. Sections of the booklet address: (1) the importance of early intervention; (2) early indicators for screening children ages birth through 60 months, including difficulties in sensory-motor skills, speech-language skills, and social skills; (3) screening for the very young; (4) the identification process; (5) characteristics of autism disorder; (6) the federal definition of autism; (7) Colorado eligibility criteria for autism; (8) the educational process for identification and individual program planning; (9) elements of effective programs; (10) common misconceptions about autism; (11) facts about autism; (12) guidelines for evaluating treatments for autism; (13) questions for parents to ask regarding specific treatment; (14) components of evaluation for autism; and (15) competencies of Colorado Regional Autism Specialists. (CR)

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Early Identification and Intervention for The Spectrum of Autism



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Why Is Early Identification Important for Children with Autism?

"Message number one is that you cannot predict outcome in the pre-school years. Message number two is that appropriate intervention in the pre-school years makes a big difference in outcome.

- Dr. Isabelle Rapin, *The Advocate*

"Differential and early diagnosis of autism are critical because the prognosis for autistic children has changed markedly since Kanner's initial work. Identifying and diagnosing autism early can provide access to appropriate services that result in better prognosis. In addition, parents benefit from having a label to put on their child's problem. It helps them understand why the child is having difficulties and helps to focus treatment efforts"

- B.J. Freeman, *The Syndrome of Autism: Update and Guidelines for Diagnosis*

". . . our understanding of these children is growing, and intensive integrated treatment approaches are helping many children make extraordinary developmental progress, the most remarkable of which is their ability to relate to others with warmth, pleasure, empathy, and growing emotional flexibility.

"The longer such children remain uncommunicative, and the more parents lose their sense of their child's earlier relatedness, the more deeply the children withdraw, and the more perseverative and idiosyncratic they become."

- M.D. Greenspan, *Reconsidering the Diagnosis and Treatment of Very Young Children with Autism Spectrum or Pervasive Developmental Disorder*

Early Indicators for Screening

Age (months)	Sensory-Motor (restricted repertoire of activities)	Speech-Language (cognitive development)	Social (relating to people and objects)
Birth (0-6)	• Persistent rocking • Inconsistent response to stimuli	• No vocalizing • Crying not related to needs • Does not react differentially to adult voices	• No anticipatory social responses (when sees or hears mother) • Does not quiet when held • Poor or absent eye-to-eye contact
6-12	• Uneven motor development • Difficulty with response to textures (e.g., problems transitioning to table foods) • Failure to hold objects or attachment to unusual objects (or both) • Appears to be deaf • Preoccupation with fingers • Over-or under-reaction to sensory stimuli (or both)	• Babbling may stop • Does not imitate sounds, gestures, or expressions • Does not relate needs • Does not give objects when requested to do so	• Unaffectionate, difficult to engage in baby games • Does not initiate baby games • Does not wave "bye-bye" • No interest in toys • Flicks toys away • Does not show distress when mother leaves room • Absent or delayed social smile • Does not repeat activities that he/she enjoys • Does not extend toys to other people • Does not differentiate strangers from family
12-24	• Loss of previously acquired skills • Hyper-or hyposensitivity to stimuli • Seeks repetitive stimulation • Repetitive motor mannerisms appear (e.g., hand flapping, whirling)	• No speech or occasional words • Stops talking • Gestures do not develop • Repeats sounds non-communicatively • Words used inconsistently and may not be related to needs	• Withdrawn • Does not seek comfort when distressed • May be overdistressed by separation • No pretend play or unusual use of toys (e.g., spins, flicks, lines up objects) • Imitation does not develop • No interest in peers

Age <i>(months)</i>	Sensory-Motor <i>(restricted repertoire of activities)</i>	Speech-Language <i>(cognitive development)</i>	Social <i>(relating to people and objects)</i>
24-36	• Unusual sensitivity to stimuli, and repetitive motor mannerisms continue • Hyperactivity or hypoactivity (or both)	• Mute or intermittent talking • Echolalia (e.g., repeats television commercials) • Specific cognitive abilities (e.g., good memory, superior puzzle skills) • Appears to be able to do things but refuses • Leads adult by hand to communicate needs • Does not use speech communication	• Does not play with others • Prefers to be alone • Does not imitate • Does not show desire to please parents
36-60	• Repetitive behaviors may decrease or occur only intermittently	• No speech • Echolalia • Pronoun reversal • Abnormal tone and rhythm in speech • Does not volunteer information or initiate conversation • May ask repetitive questions	• Foregoing characteristics continue but may become more interested in social activities • Does not know how to initiate with peers • Upset by changes in environment • Delay or absence in thematic play

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Screening for the Very Young

Checklist for Autism in Toddlers - 18 Months

Child's name _____

Date of birth _____

Age _____

Child's address _____

Phone number _____

Section A: Ask Parent

- | | |
|---|----------|
| 1. Does your child enjoy being swung, bounced on your knee, etc.? | Yes / No |
| 2. Does your child take an interest in other children? | Yes / No |
| 3. Does your child like climbing on things, such as up stairs? | Yes / No |
| 4. Does your child enjoy playing peek-a-boo/hide-and-seek? | Yes / No |
| 5. Does your child ever pretend, for example, to make a cup of tea using a toy cup and teapot, or pretend other things? | Yes / No |
| 6. Does your child ever use his/her index finger to point, to ask for something? | Yes / No |
| 7. Does your child ever use his/her index finger to point, to indicate interest in something? | Yes / No |
| 8. Can your child play properly with small toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them? | Yes / No |
| 9. Does your child ever bring objects over to you (parent) to show you something? | Yes / No |

Section B: Professional Observation/Interaction

10. During the appointment, has the child made eye contact with you? **Yes / No**
11. Get the child's attention, then point across the room at an interesting object and say, "Oh, look! There's a (name a toy)!" Watch the child's face. Does the child look across to see what you are pointing at? * **Yes / No**
12. Get the child's attention, then give the child a miniature toy cup and teapot and say, "Can you make a cup of tea?" Does the child pretend to pour out tea, drink it, etc.? ** **Yes / No**
13. Say to the child, "Where's the light?" or "Show me the light." Does the child point with his/her index finger at the light? *** **Yes / No**
14. Can the child build a tower of bricks? If so, how many? **Yes / No**
-

* To record **Yes** on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.

** If you can elicit an example of pretending in some other game, score **Yes** on this item.

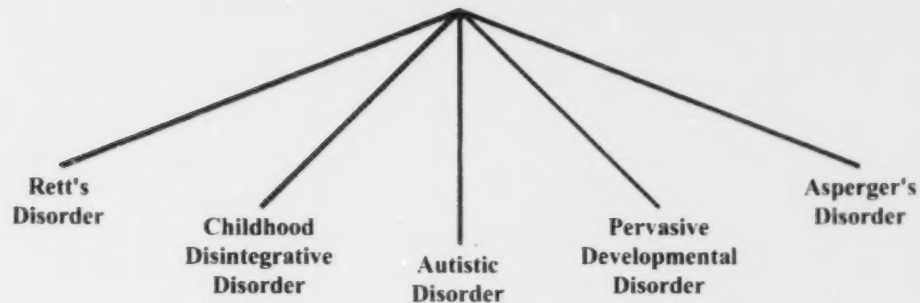
*** Repeat this with "Where's the teddy?" or some other unreachable object if the child does not understand the word *light*. To record **Yes** on this item, the child must have looked up at your face around the time of pointing.

Implications: Three or more **No** responses would indicate a need for further assessment by an autism specialist (see state criteria).

Adapted from *Checklist for Autism in Toddlers*, Simon Baron-Cohen, Department of Experimental Psychology and Psychiatry, University of Cambridge, Downing Street, Cambridge CB2 3EB, U.K.

The Identification Process

Autism Spectrum Disorders



Many professionals define autism and Pervasive Developmental Disorders (PDD) based on a diagnostic manual printed by the American Psychiatric Association (*Diagnostic and Statistical Manual of Mental Disorders*, or DSM). DSM-IV defines the following specific diagnoses: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder.

Autism is often referred to as a "spectrum disorder," meaning the symptoms and characteristics of autism can present in a wide variety of combinations from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of the behaviors in any degree of severity. Two children, both with a diagnosis of autism, can act very differently from one another and have individualized program needs.

Characteristics of Autism Disorder

A child identified with autism will exhibit characteristics under A and B, and one or more characteristics under C through F:

A. Social Participation

The child displays difficulties or differences or both in interacting with people and events. The child may be unable to establish and maintain reciprocal relationships with people. The child may seek consistency in environmental events to the point of exhibiting rigidity in routines.

B. Communication

The child displays problems that extend beyond speech and language to other aspects of social communication, both receptively and expressively. The child's verbal language may be absent or, if present, lacks the usual communicative form, which may involve deviance or delay, or both. The child may have a speech or language disorder or both, in addition to communication difficulties associated with autism.

C. Developmental Rates and Sequences

The child exhibits delays, arrests or regressions in motor, sensory, social or learning skills. The child may exhibit precocious or advanced skills development, while other skills may develop at normal or extremely depressed rates. The child may not follow developmental patterns in the acquisition of skills.

D. Cognition

The child exhibits abnormalities in the thinking process and in generalizing. The child exhibits strengths in concrete thinking while difficulties are demonstrated in abstract thinking, awareness and judgment. Perseverant thinking and impaired ability to process symbolic information may be present.

E. Sensory Processing

The child exhibits unusual, inconsistent, repetitive or unconventional responses to sounds, sights, smells, tastes, touch or movement. There may be a visual or hearing impairment, or both, in addition to sensory processing difficulties associated with autism.

F. Behavioral Repertoire

The child displays marked distress over changes, insistence on following routines, and a persistent preoccupation with or attachment to objects. The child's capacity to use objects in an age-appropriate or function manner may be absent, arrested or delayed. The child may have difficulty displaying a range of interests or imaginative activities, or both. The child may exhibit stereotyped body movements.

The Federal Definition of Autism

The Individuals With Disabilities Education Act (IDEA) defines autism as "A developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movement, resistance to environmental change or change in daily routine, and unusual responses to sensory experiences. The term autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.

Colorado Eligibility Criteria for Autism

School districts in Colorado may use the IDEA educational eligibility criteria to determine a child's eligibility for special education services. The disability "autism" is a subcategory of "Physical Disability" in Colorado.

School district personnel who suspect that a child may have autism are responsible for informing the child's parent(s) of the suspected disability. Observation that led the assessment team to this conclusion should be discussed. The school district should also inform the parent of their choice to seek a medical evaluation. However, a medical evaluation is not required for determining educational eligibility for special education services.

Educational Process for Identification and Individual Program Planning

Parents who have concerns about their child's development should contact their local school district. For children birth through five, parents should request an evaluation by contacting their school district's Child Find Coordinator. For an evaluation of a school-age child, parents should contact the principal at their child's school.

¥Screen for early identification of autism.

¥Share observations and concerns with parents.

¥Obtain parental permission for a full assessment.

¥Determine who will be part of the assessment team
(Occupational therapist, speech/language therapist, special educator, school psychologist, etc.)

The team will develop an Individualized Family Service Plan (IFSP) and/or Individual Education Plan (IEP) with goals and objectives based on individual needs. Services may include the following:

¥Adaptations

¥Accommodations

¥Curriculum modifications

¥Determination of service providers and the amount of time to be provided

¥Least restrictive environment

Elements of Effective Programs

Areas of Agreement

Earliest Possible Start to Intervention: Children who begin appropriate services earlier have better outcomes. As diagnostic procedures and tools improve, identification of children with ASD [autism spectrum disorder] occurs earlier, and some researchers are able to diagnose ASD in children as young as 15-18 months. Earliest intervention may also mean that children receive services appropriate to their needs before they have received a diagnostic label.

Individualization of Services for Children and Families:

Individualization refers to adjustments in goals, intervention strategies, and evaluation criteria for each child and family receiving services. Individualization means that each child and family's program is determined by the child's needs, strengths and interests, and the family's concerns, priorities and resources, as well as the program's overall theoretical and conceptual framework. Individualization for children also means that families may have a decision-making role and that each family's individual needs for support and participation are honored. Many programs have a core curriculum and may follow a step-by-step approach, but they design each child's program to address his or her unique needs and skills.

Systematic, Planful Teaching

Systematic teaching is instruction or intervention that is carefully thought out, logical and consistent with a conceptual or theoretical basis and involves planning, implementing, and assessing intervention steps. Planful teaching is instruction or intervention in which each step is intentional, coordinated with an overall approach, and builds toward meaningful goals. Systematic, planful teaching occurs within a wide variety of program models and can look different within each program or model.

Specialized Curriculum:

While children with ASD share instructional needs with other children, there are developmental characteristics that are specific to autism: the development and use of language, the development of appropriate social interaction skills, and restricted interests and repetitive behaviors. Programs often address these specific areas of need with core curricula. Key areas of specialized curriculum are as follows: attending to elements of the environment, imitating others, language comprehension, use of language, playing appropriately with toys, and interacting socially with others.

Intensity of Engagement:

Engagement refers to the amount of time that a child is attending to and actively participating in the social and nonsocial environment. Intensity of engagement is sometimes expressed as the percent of enrolled time that is spent in teaching interactions, or in activities in which the child is actively learning. The time that a child is engaged in learning opportunities may occur during program time and in home or community settings.

Family Involvement:

Ways that families are involved in high-quality programs for young children with ASD are as follows:

Family involvement in their own child's program such as participation of family members as key decision-makers and collaborators in determining appropriate services for their child, planning meetings, and evaluating their child's progress; services provided to children primarily because their child has ASD such as information, training and education, assistance with activities of daily living, and strategies for addressing child goals during home and community activities; services provided to families that are not directly related to ASD but may impact on overall family functioning such as obtaining or applying for housing assistance, food stamps, Medicaid, counseling or psychiatry referrals; family support and networking such as parent-to-parent support, family resource centers, family and professional collaboration and support

groups; and family involvement in the overall program such as taking part in program evaluation, serving on advisory committees, and participating in social and recreational activities.

Program Areas that Are Part of Some, but Not All, Programs Structured Environment:

Many programs arrange the environment, instructional materials, and teaching interactions to elicit, facilitate, or support specific skill attainment or development, including the use of environmental arrangements or visual cues to organize or schedule activities, to facilitate choices and to define work, play, or rest spaces.

Developmentally Appropriate Practices:

Many programs use teaching practices that have been designed for all young children, as the core of a program for young children with ASD. Developmentally appropriate programs are guided by information about child development and learning, each individual child's strengths, needs, and preferences and knowledge of the social and cultural contexts in which children live.

Intervention in Settings with Typical Children or in Natural Environments:

Many programs plan for some or all interventions to occur in settings with typical children. This may include fully integrated toddler or preschool settings, community child care, community recreation activities, and other supports in home and community settings.

Common Misconceptions About Autism

1. Autism is an emotional disorder.
2. It is difficult to distinguish between autism and childhood schizophrenia.
3. Autism occurs more commonly among higher socioeconomic and educational levels.
4. Autism exists only in childhood.
5. With the proper treatment, most autistic children eventually "outgrow" autism.
6. Children with autism do not show social attachments, even to parents.
7. Children with autism do not show affectionate behavior.
8. Most children with autism have special talents or abilities.
9. Most children with autism have normal intellectual abilities.
10. Children with autism are more intelligent than scores from appropriate tests indicate.

Facts About Autism

1. Autism is a neurobiological disorder.
2. Autism and schizophrenia differ on several important features, including age of onset, cognitive level, course and family history.
3. Autism appears to be evenly distributed across all socioeconomic and educational levels.
4. Autism is usually a lifelong disorder.
5. Many characteristics and behaviors associated with autism can improve substantially with early intervention.
6. Children with autism can and do form social attachments, although their relationships typically lack a sense of reciprocity.
7. Children with autism can and do show affectionate behaviors such as hugging and kissing.
8. Many children with autism have unevenly developed cognitive skills, but very few have savant capabilities.
9. Fifty percent of children with autism function intellectually within the range of mental retardation.
10. By age four, the IQ scores of children with autism are accurate, stable and predictive when appropriate instruments and assessment strategies are used.

Source: Wendy L. Stone, Ph.D., and Lisa Ruble, Ph.D., Treatment and Research Institute for Autism Spectrum Disorders, Vanderbilt University Medical Center, March, 1999

Guidelines for Evaluating Treatments for Autism

1. Approach any new treatment with hopeful skepticism.
Remember, the goal of any treatment should be to help the person with autism become a fully functioning member of society.
2. Beware of any program or techniques that is said to be appropriate for every person with autism.
3. Beware of any program that thwarts individualization and potentially results in harmful program decisions.
4. Be aware that any treatment represents one of several options for a person with autism.
5. Be aware that treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child.
6. Be aware that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it will be appropriate for an individual with autism.
7. Be aware that debate over use of various techniques is often reduced to superficial arguments over who is right, moral and ethical and who is a true advocate for the children. This can lead to results that are directly opposite to those intended including impediments to maximizing programs.
8. Be aware that often new treatments have not been validated scientifically.

Questions for Parents to Ask Regarding Specific Treatment

1. Will the treatment result in harm to my child?
2. Is the treatment developmentally appropriate for my child?
3. How will failure of the treatment affect my child and family?
4. Has the treatment been validated scientifically?
5. How will the treatment be integrated into my child's current program? (Do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored.)

Components of Evaluation for Autism

Historical information

- Early developmental history
- Nature/type of onset
- Associated medical problem, family history

Psychological/communication assessments

- Verbal and nonverbal skills must be assessed independently
- Assessment of social-adaptive behaviors
- Communication (not just speech) evaluation

Psychiatric assessment

- Nature of social relatedness
- Behavioral features
- Play skills
- Family/living conditions

Medical evaluations/laboratory studies

- Associated conditions
- Genetic screening
- Auditory testing
- EEG/MRI/neurological/other consultations as needed

Source: Freeman, Journal of Autism and Developmental Disorders, 27:6, 1997

Colorado Autism Network

Colorado Regional Autism Specialists have received advanced training in the following areas of competence:

- Characteristics of autism and implications
- Current trends and theories in autism
- Identification process and criteria for eligibility
- Comprehensive assessment of strengths and needs
- IFSP (Individual Family Service Plan) and IEP (Individual Education Plan) planning and objective measurement methods
- Social skills and communication assessment and interventions with autism
- Behavior assessment and interventions
- Consultation skills and knowledge of resources

Colorado Department of Education's Regionalized Service Map



To access the service of Regional Autism Resource Specialists, contact the Colorado Department of Education at (303) 866-6694.

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